Assessment of Quality of Life among Pregnant Women with Systemic Lupus Erythematosus

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ABSTRACT

Background: systemic lupus erythematosus (SLE) is a complex chronic autoimmune condition that represents a source of disability, creating a burden on the quality of life during pregnancy and affecting maternal, fetal and neonatal outcomes. **Aim:** This study aimed to assess the quality of life among pregnant women with SLE. **Methods:** A descriptive design was used. This study was conducted at Rheumatology Antenatal Outpatient Clinic at Ain Shams Maternity Hospital. A purposive sampling was used to recruit fifty pregnant women diagnosed as SLE, regardless of their education level. **Tools:** (1) an Arabic interviewing questionnaire for pregnant women with SLE, (2) a quality of life questionnaire for women with SLE, (3) a systemic lupus erythematosus disease activity index and (4) a health assessment questionnaire for women with SLE. **Results:** findings of the present study revealed that less than half of the study women had age range between 30 to 39 years. The quality of life of the study women was affected regarding its three domains; social, followed by physical and least the psychological domain. **Conclusion:** Result supported the research question, that systemic lupus erythematosus had significant negative effects on the quality of life among pregnant women with SLE. **Recommendations:** Awareness raising programs should be provided for pregnant women about SLE to reduce challenges of flare and remission during pregnancy and improve their quality of life and pregnancy outcomes. It is preferable to conduct the programs for women with SLE at premarital and preconception periods of life.

Introduction

Systemic lupus erythematosus (SLE) is a chronic inflammatory, and multi-system disease, more common among women at childbearing age. SLE is of unknown etiology but there are recognized risk factors including: environmental factors e.g. exposure for ultraviolet rays, certain medications as penicillamine and isoniazid, some virus's infections, exposure for smoking, physical or emotional stress and genetic predisposition. SLE may induce complications during pregnancy as spontaneous abortion, intrauterine fetal death (IUFD), pre-eclampsia (PE), intrauterine growth retardation (IUGR), premature rupture of membrane (PROM), preterm birth,

neonatal lupus and secondary antiphospholipid syndrome *(Zhang et al.,2018)*.

Pathophysiology of SLE embrace immune responses against endogenous nuclear antigens that are characteristic of SLE. Auto-antigens released by apoptotic cells are presented by dendritic cells to thymus cells (T cells) leading to their activation. In turn, T cells help bone marrow cells (B cells) to produce antibodies to these self-constituents by secreting cytokines that result in production of adaptive immune complexes, which amplify and sustain the inflammatory response. Moreover, SLE disease activity during pregnancy increases as a result of the increased levels of estrogen, progesterone, prolactin, T–helper cell and cytokines. Hence treatment of SLE during pregnancy involves preventing flares and reducing their severity as well as duration when they occur. Treatment may include the following safe drugs; corticosteroids as prednisone, nonsteroidal anti-inflammatory drugs as aspocid, antimalarials as hydroxyl-chloroquine and immunosuppressants as azathioprine. Some other drugs as cytotoxic drugs can't be used during the first trimester of gestation to avoid fetal congenital anomalies *(Goma et al., 2018)*.

SLE during pregnancy confers unique challenges of flares alternating with periods of remission of disease activity. Therefore maternity nurse and a multidisciplinary collaborative team must provide close monitoring and care for those pregnant women with SLE and empower them and encourage family's indulgence with women-centered self-care approach that is supported by educational guidelines. **Quality of life (QOL)** means multidimensional construct that includes the following indicators physical, psychological, and social domains *(Wallace, 2017&; Kim et al., 2018)*.

Significance of the study

Systemic lupus prevalence: an estimated 5 million people worldwide have lupus disease, in which 70% of lupus cases diagnosed are systemic lupus erythematosus; 20% with lupus will have a parent or sibling who already has lupus or develop lupus; about 5% of the newborn to women with lupus according to **(Control Disease Center "CDC", 2015)**. Furthermore, prevalence rate of SLE at Ain Shams University Hospital in Egypt is 10866 cases yearly **(Information and Statistical Center of Ain Shams University Hospital, 2015)**.

Pregnant women with SLE are prone to relapse, and remissions result in accumulation damage. This remains a challenge during antenatal management of those women with SLE. Therefore, require close monitoring for a successful pregnancy outcome and will improve quality of life with SLE as pregnancy loss rate has decreased from 43% to 17% in recent years **(Razzakh et al., 2015)**.

Aim of the Study:

This study aimed to assess the quality of life among pregnant women with SLE.

Research Question:
Is there an effect of systemic lupus erythematosus on the quality of life of pregnant women?

Subjects and Methods:

Design:
A descriptive design was used for the conducting this study

Setting:

The study was conducted at Rheumatology Antenatal Outpatient Clinic at Ain Shams Maternity Hospital.

Subjects:

A purposive sample was used. The flow rate of pregnant women with SLE at Rheumatology Outpatient Clinic at Ain Shams University Hospital was 500 pregnant women in the year 2015-2016. Accordingly, a 10% sample size (equaled 50 women) were included in the study.

Inclusion criteria:

• Pregnant women diagnosed as systemic lupus erythematosus
• Pregnant women were selected regardless of their education

Exclusion criteria:

• Hospitalized pregnant women at inpatient departments, which suffered from severe disease activity of systemic lupus erythematosus.
• Pregnant women with any other medical or gynecological diseases.

Tools of data collection:

I. An Arabic Interviewing questionnaire

entitled "Interviewing questionnaire for pregnant women with SLE", was designed by the researcher after reviewing related advanced literature. It was divided into four parts:

Part (1): was designed to assess general characteristics of the study women.

Part (2): was designed to assess previous history of SLE.

Part (3): was designed to assess obstetric and gynecological previous history.

Part (4): was designed to assess women knowledge regarding SLE during pregnancy and its treatments. Scoring system for knowledge regarding SLE was that an incorrect answer was scored as one, while correct answer was scored as two. Finally, the mean score was calculated. Overall test and retest reliability coefficients were alpha Cronbach values of 0.45.

II. Quality of life questionnaire for women with systemic lupus erythematosus was designed by **(World Health Organization Quality Of Life Brief "WHOQOL", 2004):**

This tool was in English language. It was translated to Arabic language and modified by the researcher to suit Egyptian women, in order to assess the quality of life of pregnant women with systemic lupus erythematosus. It was subdivided into five parts, *part(1)* women physical QOL included (21 items), *part(2)* women psychological QOL included (10 items), *part(3)* women social QOL included (12 items), *part(4)* women evaluation of their own QOL level included (1 item), and *part(5)* women satisfaction with their health status during pregnancy included (1 item).

➢ **Scoring system**

For each item of each domain of QOL, scoring system for the study women expression of the negative effect of SLE was calculated as follows:

• Mild effect was scored as one

• Moderate effect was scored as two

• Severe effect was scored as three

Thus, the QOL total scores ranged from 1 to 129. Accordingly, the mean score for each assessment was calculated. The bigger was the mean score, the better was the QOL. The study women evaluation of level of the quality of life as a percentage, was ranked as poor QOL if ≤ 50%, good QOL if 50-65% and very good QOL if > 65%.

Women satisfaction regarding their health status during pregnancy as a percentage also, was ranked as dissatisfied with health status if it was ≤ 50%, satisfied with health status if 50-65% and very satisfied with health status if it was > 65%. Overall test and retest reliability coefficients were alpha Cronbach values of 0.76.

III.   SLE Disease activity index, was designed by *(Petri et al., 2012)* to assess a cumulative and weighted index for health problems associated with SLE activity that included (24 items).

➢ **Scoring system**

SLE disease activity index weight scoring system was calculated as follows:

- Items from 1 to 8 was weight scored as 8

- Items 9 to 14 were weight scored as 4

- Items 15 to 21 were weight scored as 2

- Items 22 to 24 were weight scored as 1

Thus, SLE disease activity index total scores ranged from 0 to 105. The score from 0 to 35 was evaluated as mild total SLE disease activity, score from 36 to 70 as moderate activity, and score from 71-105 as severe activity. Finally, the mean score for each level was calculated. Overall test and retest reliability coefficients were alpha Cronbach values of 0.67.

IV. Health assessment questionnaire for women with systemic lupus erythematosus was designed by *(Ministry of health, British Columbia, 2012)*. This tool was in English. It was translated to Arabic and modified by the researcher to suit Egyptian women in order to assess health status for pregnant women with SLE and determine their health needs. This tool was formed of three parts: *part (1)* the degree of daily activity performance; it included (8 items); *part (2)* the need for assisting devices

with daily activities; it included (2 items) and *part (3)* the need for human help with their activities; it included (2 items).

➢ **Scoring system**

Scoring system for health assessment of women with SLE was calculated as follows:

- No difficulty with performing daily activities was scored as one

- Few daily activities performed with difficulty was scored as two

- Many daily activities performed with difficulty was scored as three

- All daily activities performed with difficulty was scored as four

So health assessment total scores ranged from 1 to 68. The mean score for each assessment was calculated. Overall test and retest reliability coefficients were alpha Cronbach values of 0.95.

Validity and Reliability:

The developed tools were reviewed for appropriateness of items, and the concepts were measured by an expert jury panel of "5 experts: 3 Professors of maternity and gynecological nursing and 2 Professors of internal medicine and rheumatology to assure content and face validity of tools. Some questions were then rephrased accordingly. Reliability: Alpha Cronbach test was used to measure the internal consistency of all the tools used in the study. Overall test and retest reliability coefficient was alpha Cronbach values of 0.67.

Ethical considerations:

- Obtaining an approval from the Scientific Research Ethical Committee in the Faculty of Nursing at Ain Shams University

before starting the study.

• Clarifying the objectives and aim of the study to the women included in the study sample and obtaining a written informed consent from each woman.

• Maintaining and assuring anonymity and confidentiality of the subject's data.

• Giving the women under study the right to withdraw from the study at any time without any effect on their health care services received in the study settings.

• No harm was done to the women or their fetuses.

d) **Pilot study:**

A pilot study was conducted in the period from the beginning of March to the end of April 2017 on 10 % of total study sample (5 women). It aimed to assess the tools of data collection for clarity and applicability and to estimate the time needed for data collection. Also to identify obstacles and problems that might be faced during data collection. Women included on the pilot study were included in the main study sample because no modifications were made except for rephrasing of some words.

e) **Procedure of the study:**

Data collection started from beginning of May 2017 till the end of October 2017. The researcher attended in the Rheumatology Antenatal Outpatient Clinic at Ain Shams Maternity Hospital on Wednesday weekly from 9.00 am to 2.00 pm. The researcher interviewed up to 3 women in each visit but each woman was interviewed separately. After greeting the study woman, the researcher explained the aim of the study and obtained a written consent to participate in the study. Then all tools of data collection were applied and collected data properly recorded within 30 minutes.

Statistical Design:

Test of significance was used to find out association between the variables using percentage distributions, means, standard deviations was used to correlate the mean scores of quantitative variables that were not following normal distribution curve. Alpha Cronbach test was used to test reliability of tools used in the study.

Result:

Table (1): Distribution of general characteristics of the study sample (n= 50).

Items	No	%
Women's age:		
< 20	6	12
20-29	21	42
30-39	23	46
Mean ± SD	28.220±5.437	
Educational level:		
Can't read & write	3	6
Primary	6	12
Preparatory	6	12
Secondary	26	52
University	9	18
Place of residence:		
Urban	30	60
Rural	20	40
Occupation:		
Housewife	46	92
Worker	4	8
Marital status:		
Married	47	94
Divorced	3	6
Income level:		
Enough	3	6
Not enough	47	94

Table (1): shows the distribution of the study sample according to general characteristics. Concerning age, 46% of the sample were at the aged 30-39 years and 42% aged 20-29 years, while the mean age for the whole sample was 28.22 (±5.437). As for their place of residence, 60% of the sample lived in urban areas. The majority of the study sample (52%) had secondary education and 12% had university education, while only 6% could not read or write. It was found that 94% of study sample were married and 92% of them were housewives. Finally 94% of them believed that they didn't have enough income.

Table (2): Distribution of the study sample according to their obstetric history (n= 50).

Items	No	%
Gravida :		
Primigravida	9	18
2-3	23	46
4-5	12	24
> 5	6	12
Para:		
Null para	17	34
Primipara	13	26
2-3	16	32
4-5	3	6
> 5	1	2
No of previous pregnancy with SLE:		
Non	12	24
1	16	32
2	12	24
≥ 3	10	20
Previous pregnancy complications with SLE (N=20):		
Abortion	17	85
Preeclampsia	2	10
Fetal congenital anomalies	1	5
Mode of delivery (N= 33):		
Normal vaginal delivery (NVD)	12	36.3
Cesarean section (CS)	21	63.7
Previous labor complications with SLE (N=12):		
Premature rupture of membrane(PROM)	11	91.6
Premature labor	1	8.4

Table (2): illustrates the distribution of the study sample according to obstetric history. About one fifth of the study women were primigravida (18%), while the rest of them were multigravida with 46% having previous 2-3 pregnancies. Meanwhile, 34% of the sample were nullipara while the rest had previous labor experience. The commoner mode of delivery was CS (63.7%). According to number of pregnancies in the presence of SLE, 32%, 24% and 20% of the sample had one, two and three or more pregnancies respectively. The reported complications during previous pregnancies were abortion (85%), pre-eclampsia (10%) and fetal congenital anomalies (5%). Also, 12 women of the study sample had associated complication with delivery, which included PROM (91.6%) and premature labor (8.4%).

Table (3): Distribution of the study sample according to their knowledge regarding SLE during pregnancy and treatment (n=50).

Items	Correct		Incorrect	
	No.	%	No.	%
Definition of SLE	12	24	38	76
Types of lupus	2	4	48	96
Risk factors of SLE	2	4	48	96
Signs and symptoms of SLE	10	20	40	80
Diagnosis of SLE	10	20	40	80
Complications of SLE	6	12	44	88
Treatment of SLE	8	16	42	84
Total mean score	8.1 ± 0.50			

Table (3): reveals that 80% of the studied sample had incorrect knowledge and 20% had correct knowledge of SLE with mean knowledge with score of (8.1±0.50).

Figure (1): Distribution of the study sample according to their source of knowledge of SLE (N= 50).
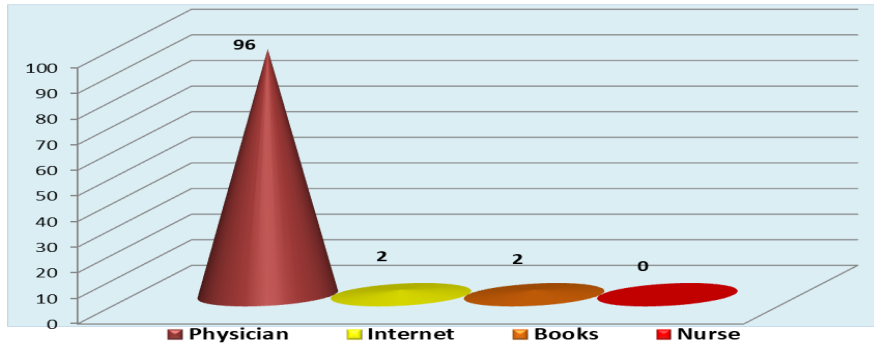

Figure (1): shows that 96%, 2%, 2% of the studied sample had their information about SLE through physician, internet, and books respectively.

Table (4): Percentage distribution of study sample QOL (N= 50)**.**

Items	Mild %	Moderate %	Severe %
Physiological QOL	0.0	94.0	6.0
Psychological QOL	0.0	20.0	80.0
Social QOL	4.0	96.0	0.0
Total mean score		40.46 ±16.43	
Items	**Poor %**	**Good %**	**Very good %**
Women 's evaluation regarding level of their quality of life	28.0	70.0	2.0
Items	**Dissatisfied %**	**Satisfied %**	**Very satisfied %**
Women 's satisfactions regarding heath status during pregnancy	24.0	74.0	2.0

Table (4): reveals that 28% of the study women considered that they have poor QOL and that 24% were dis-satisfied with their QOL. Moreover, the table the QOL was significantly affected by SLE as the total mean score of QOL was 40.46 (±16.43) which put them in the category of mild QOL

Table (5): Total mean score of the study sample according to their SLE disease activity index (SLEDAI) (N= 50).

Items	Mean ± SD
Total mean score	32.02 ± 1.51

Table (5): shows that the mean score of SLE disease activity index (SLEDAI) for the study sample was 32.02 (± 1.51) which is evaluated as mild disease activity.

Table (6): Percentage distribution of study sample according to their health assessment (N= 50).

Items	ND %	FD %	MoD %	A.D %
Dressing and grooming				
Dress1	42.0	48.0	10.0	0.0
Dress2	46.0	48.0	6.0	0.0
Rising				
Rising1	20.0	56.0	24.0	0.0
Rising2	20.0	56.0	24.0	0.0
Eating				
Eating 1	34.0	50.0	16.0	0.0
Eating2	46.0	48.0	6.0	0.0
Walking				
Walking1	34.0	50.0	16.0	0.0
Walking2	4.0	28.0	56.0	12.0
Hygiene				
Hygiene1	42.0	50.0	8.0	0.0
Hygiene2	40.0	54.0	6.0	0.0
Reach				
Reach1	2.0	28.0	60.0	10.0
Reach2	46.0	48.0	6.0	0.0
Grip				
Grip1	52.0	46.0	2.0	0.0
Grip2	52.0	46.0	2.0	46.0
Activities				
Activities1	2.0	18.0	56.0	24.0
Activities2	6.0	54.0	38.0	2.0
Activities3	4.0	16.0	66.0	14.0
Total mean score		39.92 ± 7.55		

ND= No Difficulty with all activities**, FD**= Few activities with Difficulty , **MoD**=Many activities with Difficulty and **AD**= All activities with Difficulty.

Table (6):showed that the study pregnant women with SLE had overall bad health assessment as indicated by the frequent facing of difficulty in performing most of the items of Daily Living Activities (DLA), with a very high mean score of 39.92 ($\pm$ 7.55) putting them at (AD) level.

Figure (2): Percentage distribution of studied sample according their health assessment of their needs for daily living activities support (N=50).
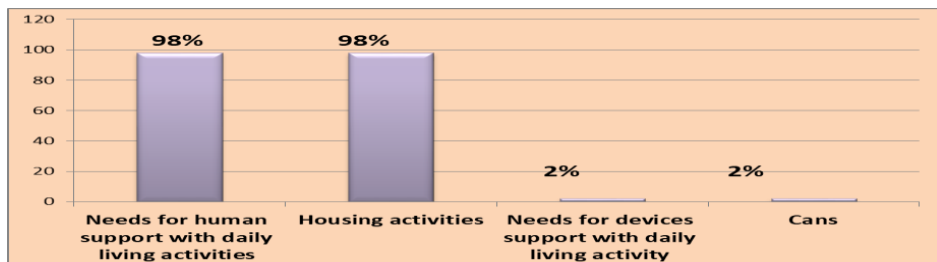

Figure (2): illustrates that despite the advanced level of difficulty in performing DLA, only one woman needed a supportive device (can), but majority of the study sample needed human help.

Discussion:

Systemic lupus erythematosus is an autoimmune chronic disease with multiple organ involvement and periods of relapse and remission that mainly affects women in the childbearing age. Pregnant women with SLE are at high risk for maternal, fetal and neonatal complications **(Yamamoto and Aoki, 2016).**

This study is a descriptive one which aimed to assess the quality of life among pregnant women with SLE.

As for general characteristics of the study sample, the results of the current study revealed that less than half of the studied sample (forty six percent) were at the age range between 30-39 years. This finding was rather comparable to that of **Wu and Di (2018)**, in which it was found that the majority of the studied sample were at the age range between 20-47 years old. That study also stated that the prevalence of high risk pregnancy increased steadily with age. This comparability of the findings could be explained in the light of the fact that SLE is more common among women in the reproductive age as a result of hormonal changes in adolescence, and perinatal period till premenopausal age.

Another study reported that around half of the study samples (forty seven percent) were at the age range between 30-40 years old, which was compatible with the findings of the current study. This correspondence was a result of that SLE affects young adults and starts in the second or third decade of life. It seemed that SLE occurred most frequently between the age ranges 20-39 years. This high predisposition of childbearing age produced a major concern for care of these age group in **Mohamed and Kamel (2018).**

Concerning other general characteristics, the results of the present

study showed that above half of the study sample (fifty two percent) had secondary education. Meanwhile, less than half of them (fourty percent) lived in rural areas. The vast majority of the study sample (ninety four percent) were married and (ninety two percent) were housewives. Moreover, the vast majority of the study sample (ninety four percent) didn't have enough income.

The findings of the present study were in accordance with **Mohamed and Kamel (2018)** , who found that more than half of their sample (fifty seven percent) had secondary education, about three quarters were married (seventy three percent) and about two thirds (sixty percent) had residences in rural areas. In addition, the current study result was also supported by **Xie et al., (2018)**, who found that three quarters (seventy five percent) of the studied sample had low education, rural residency, were unemployed, and they didn't have enough income.

These rather common characteristics of low education and living in rural areas are reflected in the high reproductive morbidity in presence of SLE, which has high prevalence among studied samples in rural areas that results from lack of access to health care services and unhealthy life style.

Hormonal and physiological changes that occur in pregnancy induce lupus activity. Likewise, the increased inflammatory response during a lupus flare causes significant pregnancy complications. Distinguishing between lupus activity and signs of both healthy and pathologic pregnancy is difficult. The risk factors and prejudicing factors of SLE influencing pregnancy outcomes and causing preterm labor include lupus activity prior to and during pregnancy, high prednisone dose, and hypertension **(Ali, 2018)**.

Regarding previous obstetric history of the study sample, the results of the current

study revealed that less than half of the study women (Thirty two percent) had at least one previous pregnancy with SLE. Furthermore, 20 women (forty percent) had history of complications associated with previous pregnancy with SLE. More than three quarters of these women (eighty five percent) had abortion, while ten percent had pre-eclampsia and about five percent had fetal congenital anomalies. Moreover, about one quarter of the sample women (Twenty four percent) had complications associated with previous labor with SLE that included PROM in most of them (ninety one and four percent) and premature labor in the rest of cases.

This study findings agreed with **Abdwani et al., (2018)**, who found that forty eight percent of the studied sample were multigravida from 2-4 times and had previous obstetric history of: gestational diabetes in about twenty eight percent, pre-eclampsia in about five percent, abortion in about forty two percent, preterm labor about in nine percent and IUFD in about seven percent.

Concerning the study women knowledge about SLE, the results of the current study revealed that the majority of the study sample (eighty percent) had incorrect knowledge about SLE. The source of knowledge about SLE in about ninety six percent of the study women was through a physician, and in two percent through books and in another (two percent) through net. These findings showed that there was no nurse role, as counsellor and health educator, available for those women regarding SLE during pregnancy.

The previous results of the study was in the same line with **Barton-Ellis (2016)**, who found that the majority of the sample had incorrect knowledge regarding SLE and their source of knowledge was experience or religious personnel. This lack of knowledge made these women reluctant as regards to health seeking behaviour.

Hence, the maternity nurse and collaborative multidisciplinary team should play important roles towards caring, and close monitoring of pregnant women with SLE. They should provide them and their families with information and self-care instructions to enhance their awareness and their adaptation regarding pregnancy with SLE. That would improve their adherence to follow-up and treatment of SLE during pregnancy, so as to improve the quality of their life and pregnancy outcomes.

The results of the current study exposed that there was a significant effect of SLE on the three domains of QOL of the study women. Psychological QOL was maximally affected as (eighty percent) of women expressed severe effects, while social QOL followed by physiological QOL were less affected as the vast majority of women (ninety six percent and ninety four percent) expressed moderate effects.

That finding are in line with **Kusnanto et al., (2018),** who found that SLE flares were triggered by physical stress resulting in fatigue and use of immunosuppressive agents. When flares were reduced, that improved general physical health and decreased joint and muscle pain, which were the most common symptoms reported , as well it increased vitality, emotional stability, and adaptive coping.

Meanwhile, disease activity index of the study sample is evaluated as mild activity. For the great majority of the study sample (about eighty three percent), comorbidity existed with their SLE; and nephritis and hypertension were the most common. The result of the present study was congruent with **Xie et al., (2018),** who found that the mean SLEDAI score was 10.1 and frequent manifestations included hair loss, rash, arthritis, low complement and proteinuria.

Never-the-less, the current study pregnant women with SLE expressed overall bad health assessment as indicated by the frequent facing of difficulty in performing most of the items of Daily Living Activities (DLA), putting them at (AD) level that meant difficulty in performing all DLAs. This result was sturdily on contrast with **Margiotta et al., (2018)**, who found that physical activity was not sufficient to meet WHO recommendations in sixty percent of the studied sample. SLA studied sample spent a median of ninety five percent every day in sedentary activities. The length of daily sedentary time was more than 6 hours in twenty five percent of them. The accumulative damage in their body systems over the years can lead to the destruction of joints and chronic pain that reduce their abilities to perform daily living activities.

As SLE is a chronic multisystem autoimmune disease that occurs predominantly in women of fertile age, the association of SLE and pregnancy mainly with active flare and especially with nephritis, has unfortunate pregnancy outcomes. There would be increased frequency of preeclampsia, fetal loss, prematurity and intrauterine growth retardation. Therefore, a pregnant woman with SLE is considered a high risk case. She should be monitored frequently during pregnancy and labor. Delivery should occur in a well-prepared health settings.

Although there is an increased risk of complications, pregnancy is not contraindicated in women with stable inactive disease receiving optimal treatment for at least 6 months prior to conception. Presence of close monitoring, with the best health care setting are a must for a successful pregnancy. Thus, planned pregnancy for women with SLE is encouraged to be allowed according to disease activity to improve fetal and maternal outcomes, and to get less severe disease flares during pregnancy.

Conclusion:

According the research question; the study concluded that systemic lupus erythematosus had significant negative effects on the quality of life among pregnant women with SLE, specially so on psychological followed by social, then physical and psychological aspects.

Recommendations:

Based on the study findings, the following recommendations are forwarded:

Awareness raising programs should be provided for pregnant women about SLE to reduce challenges for flare during pregnancy and improve their quality of life and pregnancy outcomes.

Further researches: The study suggests studying the following:

Evaluate the effect of preconception awareness raising programs on women with SLE on their pregnancy outcomes.

Investigate the effect of a multidisciplinary supportive system on the quality of life among pregnant women with SLE.

Financial Support

No funding was received.

Conflict of interest:

<u>**No**</u>   Yes

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